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Communication in a Human biomonitoring study: Focus group work, public engagement and lessons learnt in 17 European countries

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ABSTRACT

A communication strategy was developed by The Consortium to Perform Human Biomonitoring on a European Scale (COPHES), as part of its objectives to develop a framework and protocols to enable the collection of comparable human biomonitoring data throughout Europe. The framework and protocols were tested in the pilot study DEMOCOPHES (Demonstration of a study to Coordinate and Perform Human biomonitoring on a European Scale). The aims of the communication strategy were to raise

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awareness of human biomonitoring, encourage participation in the study and to communicate the study results and their public health significance. It identified the audiences and key messages, documented the procedure for dissemination of results and was updated as the project progressed. A communication plan listed the tools and materials such as press releases, flyers, recruitment letters and information leaflets required for each audience with a time frame for releasing them. Public insight research was used to evaluate the recruitment material, and the feedback was used to improve the documents. Dissemination of results was coordinated in a step by step approach by the participating countries within DEMOCOPHES, taking into account specific national messages according to the needs of each country. Participants received individual results, unless they refused to be informed, along with guidance on what the results meant. The aggregate results and policy recommendations were then communicated to the general public and stakeholders, followed by dissemination at European level. Several lessons were learnt that may assist other future human biomonitoring studies. Recruitment took longer than anticipated and so social scientists, to help with community engagement, should be part of the research team from the start. As a European study, involving multiple countries, additional considerations were needed for the numerous organisations, different languages, cultures, policies and priorities. Therefore, communication documents should be seen as templates with essential information clearly indicated and the option for each country to tailor the material to reflect these differences. Future studies should consider setting up multidisciplinary networks of medical professionals and communication experts, and holding training workshops to discuss the interpretation of results and risk communication. Publicity and wide dissemination of the results helped to raise awareness of human biomonitoring to the general public, policy makers and other key stakeholders. Effective and timely communication, at all stages of a study, is essential if the potential of human biomonitoring research to improve public health is to be realised.

1. Introduction

Human biomonitoring (HBM) studies can be used to assess exposure to existing and emerging environmental substances, and the results can help make informed decisions on health protection. Effective communication in HBM is not only important for dissemination of results; it can also help to achieve good participation rates and increase the study participants' agreement, trust and confidence in the field workers, which can help to ensure good-quality data (Cargo and Mercer, 2008; Keune et al., 2008; O'Fallon and Dearry, 2002). Therefore, it is vital that communication strategies are developed right from the start of a HBM study and allowed to evolve as the study continues (Sepai et al., 2008).

Traditionally, communication between scientists and the public has been a one-way process, but this does not take into account the public's perception and understanding nor does it involve local stakeholders in the decision-making process. A two-way approach is followed in Flanders, Belgium, where risk perception and increased dialogue with local stakeholders are incorporated into the HBM campaign (Keune et al., 2008). Community-based participatory research, in which the community is involved from the start with the design of the study, interpretation of results and consequent action (Balazs and Morello-Frosch, 2013), takes this a step further. Benefits of this approach include community trust in the researchers, increased use and relevance of the data and improved dissemination (Balazs and Morello-Frosch, 2013; O'Fallon and Dearry, 2002). This approach has been successfully applied in studies where specific pollution is a concern; HBM research in Ohio after perfluorooctanoate contamination of a residential water supply raised community awareness and modified individual and stakeholder behaviours (Emmett et al., 2009). It has also been applied in general environment health research; the Northern California Household Exposure Study found the approach increased environmental health literacy and generated individual and policy action to protect health (Brown et al., 2012).

Communication of HBM results to participants varies by study but traditionally the 'clinical ethics' approach has been used. The Canadian clinic-recruitment based 'Maternal–Infant Research on Environmental Chemicals' study (Haines et al., 2011) and national HBM studies in Portugal (Reis et al., 2008) have used this approach in which just the aggregate results are provided or individual results are given but only when health-based guidance values and interventions are available (Morello-Frosch et al., 2009). Other studies have moved towards a more open approach providing both individual and aggregate levels results, even if there are no clear health guidelines. Examples include the household recruitment-based Canadian Health Measures Survey (Haines et al., 2011), the Flemish HBM program (Schoeters et al., 2012) and the German Environmental Survey (Schulz et al., 2007).

Communicating individual results when there is a lack of health guidance values to interpret the data may empower individuals or could cause worry and concern (Brody et al., 2007). Washburn's experience from interviewing HBM study participants suggested that frustration due to an individual's limited ability to take action to protect themselves from future exposures is also an issue (Washburn, 2014). Individuals may interpret the results themselves and take inappropriate action, for example; detection of chemicals in breast milk may cause mothers to stop breast-feeding. Arendt discussed how this can occur if the communication strategy of such HBM studies is not in line with public health messages for breast milk studies (Arendt, 2008). A discussion with scientists and local stakeholders in Belgium for the centre of Expertise for Environment and Health concluded that transparency should be given priority over a concern that individuals may interpret the results differently to the scientists (Keune et al., 2008).

However, such research needs to consider carefully how information is communicated and what public health messages are used (Arendt, 2008). Wu et al. (2009) evaluated the impact of participating in a HBM study measuring polybrominated diphenyl ethers in breast milk, on breast feeding practices. The participants were provided with clear information about the benefits of breastfeeding and careful consideration was given to the provision of the individual results (by telephone). Follow up found that participants who were concerned about the results were reassured by the study information, the personal communication and the message 'breastfeeding is best'. Researchers need to be clear about the scientific uncertainties, provide information on how to reduce exposures and put the results into context, for example, by making comparisons with other populations (Brody et al., 2014).

A communication strategy, to take into account these issues, was included in the framework and protocols developed by The Consortium to Perform Human Biomonitoring on a European Scale

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(COPHES) to enable the collection of comparable HBM data throughout Europe. The framework and the protocols were tested in DEMOCOPHES (Demonstration of a study to Coordinate and Perform Human biomonitoring on a European Scale), a pilot study in which 17 European countries assessed exposure to cadmium, environmental tobacco smoke, phthalates and mercury in children and their mothers by sampling urine and hair (Joas et al., 2012).

The communications strategy was developed to encompass each stage of the DEMOCOPHES project from the publicity and recruitment of participants, communicating individual and aggregate results, final conclusions and recommendations for a future European-wide HBM project. The objectives of the communication strategy were (1) to promote public awareness of human biomonitoring, (2) to enhance recruitment and informed consent of mothers and their children from 17 countries across Europe, (3) to report individual and collective results and explain their public health significance, (4) to ensure transparency and openness towards stakeholders within participant countries and across Europe, and (5) to safeguard the translation of results into precautionary and preventative policy.

This paper discusses the development of the communication strategy, the tools and materials used in the DEMOCOPHES pilot biomonitoring study, and the lessons learnt.

2. Methods

The DEMOCOPHES pilot study aimed to recruit 120 children aged 6–11 years old and their mothers up to 45 years old per participating country (60 pairs for Cyprus and Luxembourg). Children and mother pairs were recruited from two sampling locations according to the degree of urbanisation using the upper and lower category (big city vs. rural) in each country, not including hot-spots. Urine samples were measured for cotinine, cadmium and a number of phthalate metabolites. The hair samples were tested for mercury. Some countries also measured bisphenol A in urine. Details on the study protocol have been published (Becker et al., 2014).

The communication work built on knowledge gained from an assessment of the current issues in HBM and a stakeholder analysis by the Expert Team to Support Biomonitoring in Europe (ESBIO) (Reis et al., 2007). The initial communication plan was outlined in the protocol written by COPHES (Becker et al., 2014; Casteleyn et al.,, in this issue). Specific and dynamic strategies were designed for the study participants, the general public, policy makers and the media and tested in the pilot study. These strategies took into account participation and exchange between the whole range of different stakeholders (general public, study participants, general medical practitioners, paediatricians, local authorities (health, education), school teachers, regulators, scientists, public interest non-Governmental organisations, industry, and policy officials) and also considered communication at regional, national and EU levels.

The main communication tools, materials and activities developed to address the communication objectives of the project are listed in Table 1. A sample of materials used in the study is shown in Fig. 1. A communication plan was created and updated as the project progressed; it listed the tools and materials required for each audience and the time frame for releasing them.

2.1. Publicity

To promote public awareness of HBM and to ensure transparency and openness towards stakeholders two periods of extensive communication campaigns were identified: before and at the start of the sampling period and at the dissemination of the results. Press releases were sent at these stages to journalists, journals, press officers, policymakers and other relevant stakeholders in each country. Flyers and posters advertising the work of the HBM project were prepared for the different stakeholders. These briefly described the aims of the study and provided details on where to get more information.

Web-pages were created to inform participants, the public and stakeholders of progress throughout the study. The EU website,[1] provides information in English on both COPHES and

Table 1
The main communication tools, materials and activities developed to address the communication objectives of the project.

Communication objective	Tools/materials/activities
(1) To promote public awareness of human biomonitoring	Press release Articles in national and regional newspapers Flyers, posters, banners Study information leaflets for the public and children Newsletters EU and national websites A TV documentary
(2) To enhance recruitment and informed consent of mothers and their children from several countries across Europe	Invitation letters and study information Information meetings with mothers Consent forms and reply cards Public insight work
(3) To report individual and collective results and explain their significance to public health	Guidance on communicating results for participating countries A professional network to discuss interpretation of the results and communication strategies Study participants results letter, Chemical information factsheets Meetings with study participants Layman's study report Technical study report
(4) Ensure transparency and openness by informing diverse stakeholders about aggregate results across Europe and within participant countries	Policy information sheets and meetings with policy officials
(5) To safeguard translation of results into precautionary and preventative policy	EU and national websites Study information leaflets for general practitioners Scientific publications and presentations at scientific congresses Newsletters Press releases Articles in national and regional press

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Fig. 1. A sample of communication documents used in the study.

DEMOCOPHES and is linked to the national websites. It explains the nature and aims of the pilot study and was regularly updated with documents such as the study information leaflet and frequently asked questions, information on HBM events and news from the projects and wider afield. The website has a media section[2] with a press kit, a selection of press releases and press articles and a link to the study documentary.

COPHES gave simple guidance to participating countries on information that should be included on their national websites in their national language(s), such as the project and funding logos, study description, all communication material (letters, leaflets, flyers), legal information on funding, the protocol and ethical committee information. At the end of the study, a layman's report (DEMOCOPHES, 2013a) and the technical report (DEMOCOPHES, 2013b) were published on the EU and national websites.

Visitors to the EU website could subscribe to an email newsletter. Three newsletters were circulated by email and published on the website. They provided updates of the COPHES work to develop the HBM framework, progress of the DEMOCOPHES pilot study, reports of consortium meetings and training workshops, country-specific experiences in biomonitoring and discussion of current issues in HBM, such as the World Health Organization (WHO) work on mercury.

An online information exchange and communication platform with a 'contact us' page and a help-desk were available. Visitors could also sign up for access to a forum for discussion on all aspects of the study.

Ways suggested in the protocol to contact the target populations included:

- Advertising the study and website on radio, information adverts in local newspapers.
- School liaison visits – where appropriate.
- Distribution of leaflets in general health practitioners and health centres and where mothers may take younger children, for example, play groups.
- A short video on the national websites giving an overview of the project.

2.2. Communication at recruitment and during sampling

COPHES advised recruitment via a population registry because this method would enable a strictly random population sample to be targeted. If this was not feasible, recruitment via schools was recommended. The rationale for the recruitment strategy and the options considered has been discussed (Becker et al. 2014, Fiddicke et al., in this issue).

The inclusion criteria were mothers, foster- or step-mothers aged ≤ 45 years old and their children aged from 6 to 11 years old. They must have been living in the same area (city/ village) for five or more years and only children who live most of the time (>16 days/month) with their mother were included. Only one child per mother (randomly selected) was included in the study. Immigrants and children from immigrant families were not excluded as long as they had sufficient ability in one of the national languages. Exclusion criteria were mothers or children living in hospitals, institutions or being homeless and participants with metabolic disturbances (diseases of the liver, pancreas or kidneys) or abnormal urine excretion (samples with creatinine concentration below 30 mg/dL or above 300 mg/dL were excluded from the analysis (WHO, 1996)).

Potential participants received an invitation letter, an information leaflet, a reply card and consent form. In most of the countries, children received a tailored leaflet with dinosaur cartoon characters explaining the study in age appropriate language. Volunteers who met the inclusion criteria then received a confirmation letter; a consent form, urine containers and an

[1] http://www.eu-hbm.info accessed 05/09/2014.
[2] http://www.eu-hbm.info/euresult/media-corner accessed 05/09/2014.

instruction leaflet for urine sampling. For details on this procedure see (Fiddicke et al., in this issue).

2.2.1. Recruitment material

Templates were developed by COPHES for the invitation letter, consent form and information leaflets as part of the European protocol. These were adapted and translated by the teams of the 17 DEMOCOPHES implementing countries into national languages. The standard information that all countries needed to include is detailed as follows.

The invitation letter – Participants were invited to take part in the DEMOCOPHES study which, depending on the participating country, involved an appointment held either at the participant's home or at a local centre (school building, health centre, etc.) which would last about one hour to provide a first-morning spot urine sample, answer a questionnaire (on home and workplace environments, possible contact with chemical substances, food intake and the use of personal-care products) and have a small sample of hair cut from the scalp.

The participant information sheet – This included a summary of the research project, details on when and how the results would be communicated, an outline of the inclusion and exclusion criteria for the study (as listed above), an explanation on how privacy and confidentiality would be maintained, and that they had the 'right not to know' their results.

The consent form – At the appointment, there was time for the participant to ask any questions, and then they were asked to sign this form acknowledging that they had read and understood the information provided. They were asked to agree to the use and storage (up to 10 years) of their hair and urine samples and questionnaire data in confidence, by approved researchers for public and environment health-related research purposes; to be contacted unless they preferred not to receive their results; to acknowledge that their participation was voluntary, and that they could withdraw at any time without giving any reason. An assent form for children was also developed and used in countries where this was appropriate or mandatory. The consent form was adapted by participating DEMOCOPHES countries based on national ethical requirements. For example, one country required consent to be obtained from fathers, another required consent from fathers where the mother did not have sole custody. Another country was required to provide more information on the storage of samples.

2.2.2. Evaluation of recruitment material

COPHES evaluated the proposed recruitment material by collecting feedback from the public via two public focus groups and a 'people panel'. The aim was to determine whether participants understood what would be involved as a study participant, whether sufficient information had been provided and whether the documents would encourage them to take part. The feedback was used to improve the documents before they were sent to the participating DEMOCOPHES countries and translated into national languages.

The public insight work was conducted in the UK because it was both a COPHES and DEMOCCOPHES participating country. Due to time and cost constraints, COPHES did not run public insight work in all participating countries but suggested that countries could conduct their own focus group work to assist them when adapting the templates to reflect cultural differences or slight differences in study protocol, e.g. recruitment via schools or registry.

2.2.2.1. Focus groups. The focus groups were held in January 2011; Mothers from urban areas in London were invited to attend the first focus group at a viewing facility in the centre of London and Mothers from rural areas in Devon were invited to the second focus group, which was held at a hotel in Exeter. There were 18 participants split across the two groups, some were drawn from the Health Protection Agency's (now part of Public Health England, PHE) people panel (see later for details) while others were specially recruited for the focus groups.

The focus groups were conducted by trained facilitators of the PHE public involvement team. The voluntary nature of participation, permission for audio-recording and group conduct rules, including strict confidentiality, respect for differing perspectives and the need to allow all participants to have the opportunity to share perspectives, were established prior to all sessions. Participants received a modest payment to cover expenses at the end of the session in appreciation for their time and participation.

Each focus group was asked to review three documents prepared for the mothers taking part in the pilot project; the invitation letter, the information leaflet and the consent form and to provide feedback on the questionnaire. The documents were sent in advance of the sessions so that the participants could read the documents at their leisure. The first part of the focus group session consisted of a short introduction and background to the study and to general issues around environment and health to help focus group members understand the aims of the study. The facilitators used a few select questions to ask, but not hamper, free flowing discussion as detailed in Table 2.

2.2.2.2. People panel. The people panel was set up to find out what people know and think about public health issues and hazards such as infectious diseases, chemicals, poisons and radiation. The panel is asked to comment on advice provided on the website or printed materials and encouraged to have a say in the way PHE plans, develops and provides services.

Emails were sent to 315 members (men and women) asking them to evaluate the study invitation letter and information leaflet. They were given two weeks to review the documents and answer a questionnaire; the questions are listed in Table 2.

2.3. Communication and dissemination of results

The objective was to report individual and collective results and explain their public health significance to the public and the policy makers at a national and EU level. Each country could choose which guidance values to use because this decision might be influenced by distinct toxicological judgment and policy at a national level. COPHES prepared guidance documents for the participating countries to help interpret the biomarker values taking into account data from individuals' questionnaires and comparisons with health-based guidance values and population reference values. If no health-based guidance values were available, participating countries were advised to use the 90th/95th percentile of a comparable reference population in the respective

Table 2
Questions asked at the focus group workshops and sent to the people panel.

- Is it clear what the mother is being asked to do?
- Is the language clear and easy to understand?
- Does the leaflet explain what a mother would need to know about biomonitoring?
- Is the language too technical or full of jargon? (For example: what are phthalates?).
- Is there too much information/too little or about right?
- Do you think the letter/leaflet would encourage or discourage people from taking part in biomonitoring? Please give reasons for your answers.
- What more could be said or done to encourage participation?
- Are there any ways in which the information could be improved?
- Is there anything missing?

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Table 3
Guidance values used for the overall DEMOCOPHES results.

Chemical	Children	Mothers	Reference
Cadmium	0.5 μg/L HBM I 2 μg/L HBM II	1 μg/L HBM I 4 μg/L HBM II	Schulz et al. (2011)
Cotinine	50 μg/g creatinine to distinguish between smokers and non-smokers		Riboli et al. (1995)
Mercury	2.3 μg/g	2.3 μg/g	JECFA (2006)
Sum of DEHP metabolites 5-oxo- and 5-OH-MEHP	500 μg/L HBMI	300 μg/L HBMI	Schulz et al. (2011)
Bisphenol A	1500 μg/L HBMI	2500 μg/L HBMI	German Human Biomonitoring Commission (2012)

country or region or another country. Noting that reference values are not health-based and that the reference population may not reflect the study population in terms of exposure and lifestyle factors so would add greater uncertainty to the comparison.

The guidance values used for the overall DEMOCOPHES results are listed in Table 3. Cadmium results were compared with the HBM I and HBM II value; health-based "HBM-values" derived by the German Human Biomonitoring Commission. HBM I values correspond to the concentration of a substance in human biological material below which adverse health effects are not expected. HBM II values correspond to the concentration of a substance in human biological material above which there is an increased risk of adverse health effects in susceptible individuals in the general population (Schulz et al., 2011). For cotinine no health based guidance values were defined but the results were classified by (I) below limit of quantification, (II) above limit of quantification and the generally accepted cut-off value of 50 μg/g creatinine to distinguish between smokers and non-smokers (Riboli et al., 1995). For mercury the guidance value defined by the Joint Food and Agriculture organization of the United Nations (FAO)/WHO Expert Committee on Food Additives (JECFA) at their 67th meeting in 2006 was used (JECFA, 2006). The di(2-ethylhexyl) phthalate (DEHP) metabolites: (5oxo-mono(2-ethylhexyl) phthalate (5-oxo-MEHP) and 5hydroxy-mono(2-ethylhexyl) phthalate (5OH-MEHP)) were compared with the HBM I value in urine (Schulz et al., 2011). For the other phthalate metabolites measured no health-based guidance values are available so it was recommended to report the values as a distribution and make

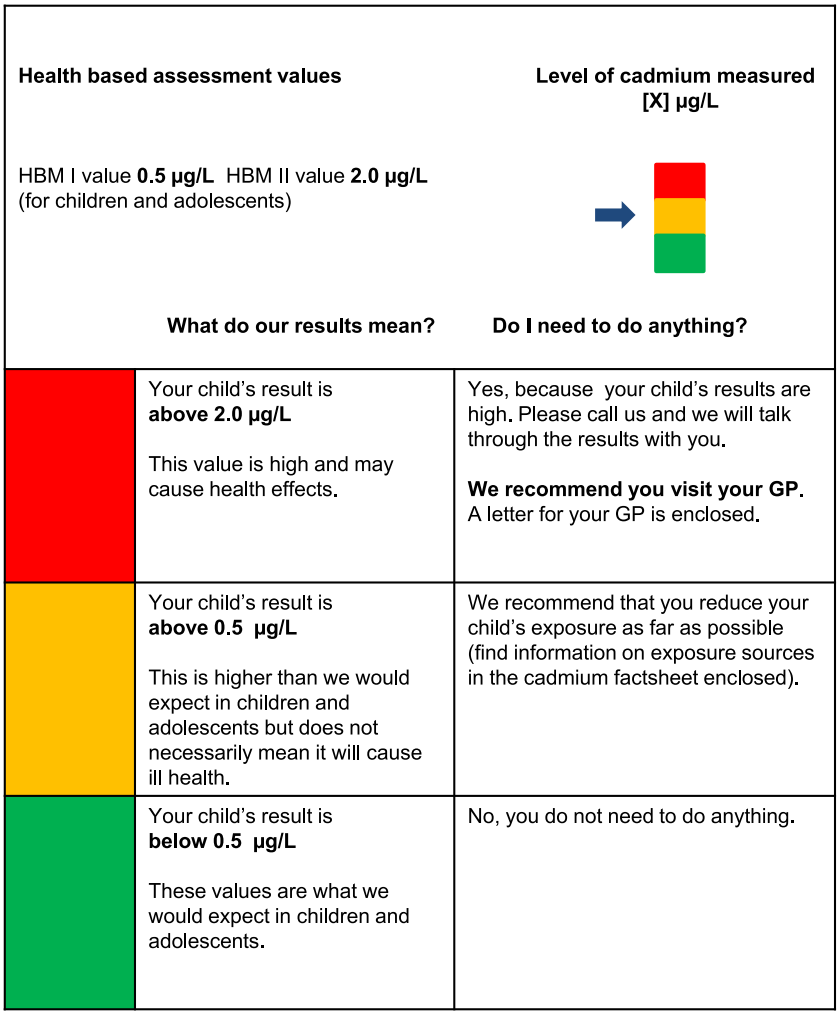

Fig. 2. An example of the traffic light system used to express the cadmium results in children. The arrow was moved to reflect the level of the chemical measured in relation to the guidance value.

comparisons between geographical or other groups. For Bisphenol A, the HBM I guidance values were used (German Human Biomonitoring Commission, 2012).

A communication plan for dissemination of results was developed to ensure that communication was coordinated. Dissemination was proposed in a step by step approach: (1) communication of the results to the participants of the study, (2) communication of the aggregate results to the general public and stakeholders with the policy recommendations, and (3) communication of the aggregate results at European level. At a national level, ethical requirements needed to be taken into account, for example, one country had to report individual results to the family doctors of the participants. Depending on the country, a symposium was organised at the national level before or after the communication of the aggregate results at European level.

2.3.1. Communication of HBM results to study participants

Communication to study participants took place as early as possible, unless the participant chose not to be informed in accordance with each country's ethical requirements. The experiences with ethical approval and data protection are discussed in (Casteleyn et al., in this issue). Each participating mother received a letter with her and her child's results, explaining that, this study gave only a snapshot of their exposure and that finding a measurable amount of a chemical in their urine or hair did not imply that the levels would cause an adverse health effect. The results letter used a 'traffic light' system, Fig. 2. Chemical factsheets were enclosed, which provided information on sources, routes of exposure, possible effects and ways to reduce exposure.

If results were above the health-based guidance value, immediate personal communication to the study subject was required, and participants were advised to visit a health practitioner, which depending on the country was the study doctor, their general practitioner (GP), an environmental outpatient clinic or a physician specialised in environmental medicine. They were provided with a letter written for their health professional, which explained the study and advised them on what action to take. For example, in the UK, a health examination and kidney function tests were recommended if urinary cadmium levels were above 4 μg/L for mothers and 2 μg/L for children. Some countries also sent study information leaflets to GP's. This included more information on the study, who the GP could speak to for advice and what to do if a participant contacted them.

2.3.2. Communication of the aggregated results

The country level aggregated results were unlinked from personal data to ensure confidentiality. The 90th percentiles and mean values of the overall results were presented, and each country was represented as a percentage of the DEMOCOPHES countries average.

The aggregated results and conclusions of COPHES and DEMOCOPHES were presented at the Cyprus Presidency Conference, 'Human Biomonitoring: Linking Environment to Health and Supporting Policy', held in Larnaca in October 23–24, 2012 (Cyprus Presidency of the Council of the European Union, 2012a).

In each DEMOCOPHES implementing country, policy officials were sent a tailor made factsheet explaining the anonymous, aggregated results and relevance to national policy. Meetings were also held either before or after the Cyprus Presidency Conference to disseminate the aggregated results and explain the public health significance to the study participants, scientists, policy officials and the press. More information on this can be found in the DEMOCOPHES technical report (DEMOCOPHES, 2013b).

2.4. Communication training

Workshops on communication for national focal points and fieldworkers organised by DEMO/COPHES were held in Brussels, December 2011 and in Copenhagen, March 2012. In Brussels, there were presentations on communicating results by the French Institute for Public Health Surveillance and participants' responses to receiving results from a study into endocrine disrupter compounds in California (Adams et al., 2011). The objective of the workshop in Copenhagen was to develop and understand the

Table 4
Insights from the qualitative work.

Comments during the insight work	Recommendations
Was the language suitable for the audience?	Remove scientific terms or provide definitions/ explanations of terms.
What does this mean, it is too scientific?	The information needs to be more positive by selling the benefits of the research and removing passive language.
Words such as 'exposure' and 'dataset' were not understood.	
'People have to be wooed to take part'	
What concerns did people have?	People may need some reassurance that there is not a special reason why they have been asked to take part in the research. Explain the sampling process is random and not because the mother/ child have been exposed to chemicals.
Why have you chosen me?'	
'Why are you recruiting in rural and urban areas?'	Develop a video to use online to explain the project to participants. This could be supported by an online forum for people to raise questions and concerns.
'Why are you asking me how much I earn?'	Inform participants of the type of questions that will be asked and why we might ask them. Explain why you are asking specific questions e.g. on social-demographic status.
Tell me about the chemicals. 'If it says I have high Cadmium, I have no idea what these things are?'	It is not necessary to go into all the health effects of the chemicals but provide a brief description of them and where they are commonly found in the environment. For example Cadmium is present in electrical batteries and cigarette smoke. If people want more information on pollutants they could be directed to download factsheets on specific chemicals from the website.
What about other chemicals?	Consideration should be given to the geographical location of a participant. The Exeter Group demonstrated that people living in the South West of England wanted to ask more questions about chemicals. For example they were aware of the risks from radon gas due to its presence in the region. As a result they want to have more information about environmental pollutants. A set of frequently asked questions tailored for people in each region could be considered.
Practicalities	People are busy, make it clear in the initial information how long the appointment will take and that appointments are available at times to suit the study population.
Will the appointment be at a convenient time?	
Where will the study centre be?	If not visiting homes, give people a choice of venues or provide information on where it will be in the initial letter.

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theory behind participatory research and risk governance and to provide practical support to each DEMOCOPHES implementing country. Training workshops on fieldwork and sampling also discussed the importance of communication styles including the use of terminology and body language, when obtaining consent and asking the questionnaire. More details on the training can be found on the website.

A network with medical professionals and communication experts was established for participating countries to exchange views and expertise on interpretation of the results and on good communication strategies. To aid discussion of the results, the network and the national focal point from each DEMOCOPHES implementing country were invited to participate in three web conferences, using the Elluminate Live program (Blackboard Inc., Washington, DC, USA).

3. Results

3.1. Communication at recruitment and sampling

3.1.1. Feedback from focus groups and people panels

In London, the focus group was composed of eight mothers aged between 38 and 52 (most were in their 40's) with children in the age range of four to 17 years. Four were panel members and four were recruited specifically for the focus group. The London group comprised mothers living in urban or suburban areas, for example, the London Boroughs of Putney, Newham, Richmond and Merton and the rest came from the suburbs of Kingston, Leatherhead and Epsom. The focus group in Exeter was composed of eight mothers aged between 30 and 54 with children of school age and teenagers (most were mothers in their late 40's). Seven mothers were recruited for the day, and one was a panel member. The Exeter group comprised mothers living in rural communities and villages in Devon those of Paignton, Whimple, Rewe, Honiton and Rockbeare. Across the two groups, there included both stay-at-home mothers and those who were in paid employment. Those who worked included the following professions: a psychotherapist, a housing association worker, a musician, a community development officer, a scientist, a healthcare professional, a general practice manager, a veterinary nurse and a farmer.

For the people panel, of 312 emails sent there was a 7% response rate (22 replies), which is similar to the typical response rate from the panel of 10%. Responders included men and women, but data were not collected on age or occupation. The low response may have been due to the length of the documents to read, a lack of interest in the topic, or they had taken part in one of the focus groups. Despite this, the comments were similar to those received during the focus groups and so enforced the overall recommendations from the focus group research.

Table 4 shows insights from this qualitative work and the recommendations on how to address the issues raised. The participants said that the language was too scientific in places and not all the words were understood so this could discourage people from talking part. They also said that if they had been asked to take part they would wonder whether there was something wrong with them. More details about the chemicals were requested and some practical details about location of the appointment were missing. For the questionnaire, they wanted to know why specific questions on, for example, income, were being asked. In response to the recommendations, the documents were reviewed for scientific jargon, which was simplified. In the information leaflet, extra focus was given to the explaining the type of questions that would be asked in at the appointment, such as, questions on dietary habits, where they live, use of personal-care products, etc. Guidance was provided to the fieldworkers, which explained why specific questions were asked so they could inform the participants. A list of frequently asked questions and more information on the uses, sources and possible health effects of the chemicals were published on the website.

Lesson learnt: Public insight research can provide feedback on communication materials from the target audiences to ensure it is fit for purpose. Materials for recruitment and dissemination of results should be evaluated during development and after the changes have been made.

3.2. Experiences during the study

Recruitment was difficult and took longer than anticipated for most countries but all, except two, managed to recruit the minimum number of study participants. COPHES recommended collecting data on the non-responders via reply cards or directly contacting people to find out why they would not participate, but this was not always possible. Often those who were not interested in participating were too busy to take part and so were not likely to fill in a response card. In countries that chose to recruit participants via schools, considerable time and effort before recruitment could start was required to contact school governors, local authorities and heads of schools and to encourage community/teacher/school involvement. One country held a HBM information day at the school, and this resulted in higher response rates compared to other countries.

Lesson learnt: Contact with schools needs to occur as early as possible, at least a year in advance, in order to schedule the sampling into the next school year and consider how the work could support the curriculum. Information days for the parents, teachers and pupils would also enhance engagement and response rates.

Strategies to engage and interact with study participants will vary according to the type of project and are subject to the usual constraints of time, budget and imagination. One country posted a short video on 'YouTube' explaining the study, but social media was not utilised to its full potential in this study for several reasons such as time and finance constraints, or a lack of experience in using such resources. The recruitment strategy required potential participants to sign-up and arrange appointments via letters and telephone calls but one country successfully used on-line methods such as school intranets and e-calendars. This may be a preferable method for future studies because it allows participants to go on-line at a convenient time for them. Furthermore, it could help to reduce the time and costs involved in recruitment administration.

Lesson learnt: Consider how modern communication technologies and social media can be used for recruitment to enhance response rates.

Feedback from study participants suggested that the information leaflet in this study was too detailed and not always read. The general consensus from the participants was that they would prefer less information. Ethical committees often recommend that an extensive amount of information is given during the introduction or initial contact so that the potential participant is 'well informed'. Thus, it is a recommendation that the first contact information leaflet is brief and once a participant volunteers, BUT before they consent – further information should be given to ensure that participants understand what is involved. Detailed information should also be available on the website and the opportunity to ask questions is essential at all stages of the project. The information leaflet for children was popular and may even be useful for adults. Lessons learnt from the recruitment strategy are discussed in detail in (Fiddicke et al., in this issue).

Lesson learnt: Do not overload potential participants with too much information. Provide initial information that is friendly (i.e. active tense, no jargon, see Table 4), simple and short. If people are

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interested in taking part, then provide them with more detailed information. Do ensure that leaflets are tailored to young children.

3.3. Dissemination of results

It became clear during the training workshops (see Section 3.6) that variations in the organisation of the health care systems and different policies for public health and cultural needs would affect to some extent, how each country could report back the results. It was agreed that each country would need to adapt the result letter to take account of national differences. In some countries where there is high fish consumption relatively higher levels of mercury were measured. It was important to balance the information of mercury levels with public health messages on eating fish. Advice such as recommendations for how much fish people should eat, the types of fish that contain relatively higher levels of mercury and the health benefits of eating fish was included in the results letter.

Lesson learnt: The communication documents should be considered a template which countries can adapt to suit cultural needs and national policy on environmental chemicals and public health. Involve social scientists at the beginning of the study to help with risk communication.

3.4. Publicity

The start of the project and of the recruitment period was covered by several newspapers in participating countries and at European level. Project websites,[3] both at European and at national level, were kept updated with progress and project documents throughout the project.

The results were presented at the final DEMOCOPHES/COPHES conference in Cyprus (Cyprus Presidency of the Council of the European Union, 2012a; European Commission, 2012). It was well attended and attracted more than 140 participants from 30 countries (27 European countries, Japan, USA and Israel), representing advocate groups, EU and Member State authorities, policy makers, industry, WHO, the European Food Safety Authority, the European Environment Agency and academic institutions. As a result, several European journals showed interest and press articles receiving wide coverage were published (Cyprus Presidency of the Council of the European Union, 2012b). A selection of press releases and articles as well as a documentary are available on the EU website.[2]

The DEMOCOPHES results on mercury were used for an economic calculation of the cost of the actual exposure of Europeans to this widespread heavy metal (Bellanger et al., 2013), published in January 2013, a week before the voting on the Mercury Treaty in the United Nations and received positive attention.

3.5. The EU website

During the study, communication specialists reviewed the website and made recommendations on how to improve it which included (1) to ensure that the target audiences are evident, (2) to provide a clear mission statement, (3) to use a splash screen to introduce the two projects, (4) to use a XML site-map and (5) to optimise the website for mobile devices.

Lesson learnt: Consult communication specialists early in the process to work with study scientists on the website design and content.

[3] http://www.eu-hbm.info/democophes/project-partners accessed 05/09/2014.

3.6. Communication training

The training sessions enabled participating countries to discuss the strategy, learn from each other's experiences and provide feedback to develop and update the communication strategy. The professional network and web conferences were useful for addressing individual countries' concerns, and the web conferences were highly attended. Web conferencing meant that more people could participate, and the time and costs involved could be kept to a minimum. Web conferencing was also successfully used for other aspects of the study; the laboratories' external quality assurance exercises for chemical analyses in urine (Schindler et al., 2014) and in hair (Esteban et al., in this issue).

Lesson learnt: Training workshops for participating countries, a professional network with key scientists and physicians involved in the study from each country, and web conferencing facilities to facilitate discussions, are useful tools for developing the communication strategy.

4. Discussion

For a study that involves multiple countries consideration is needed for the numerous organisations, the different languages, cultures, policies and priorities. The communication strategy needs to be flexible as it was impossible to provide a 'one-size fits all' set of communication documents. Templates with essential information clearly indicated should be provided and then each country can adjust the materials to take into account their specific needs and requirements.

The EU and national websites were important tools for raising awareness and communicating the study to a wide range of stakeholders. Bates and colleagues' report on a workshop to discuss biomonitoring study design, interpretation and communication concluded that a website should be a high priority, enabling the data to be shared with other scientists (Bates et al., 2005). Researchers also have an obligation to the participants and the general public to be transparent and honest about the design and implementation of the study as well as how the results and other outputs will be used. The EU and national websites were used to communicate such information to the study participants, the public, the media and others. A study website requires sufficient resources for it to be truly effective; the time and effort needed to maintain and update it should not be underestimated.

Qualitative public insight research by social scientists can help to develop tailored communication materials for study participants by identifying what people know and why they have a given view, which can help to maximise recruitment rates (Cargo and Mercer, 2008). Members of the public from the UK were consulted on the recruitment material, and their comments were used to improve the materials but qualitative research involving other countries would have provided a more European perspective.

Greater involvement of social scientists throughout the project would have been beneficial for community engagement (Keune et al., 2008). Balazs and Morello-Frosch, 2013 describe community-based participant research as a continuum of effort. The more the community are able to participate in the research process the greater the community engagement. The countries which used schools to recruit participants engaged with the school community holding information meetings at the start of the study and for dissemination of the results. Engagement could be further increased by contacting schools at an earlier stage so that the study could be designed in line with the school's curriculum. In future European HBM studies involving recruitment via schools, it is recommended that a school network is established. This would enable the schools to share experiences and to learn about other countries and cultures, and may improve participation.

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The EU states that participants in HBM studies have the right to know their individual results, but also not to know them if they wish (Casteleyn et al., 2013; Sepai et al., 2008). A key aim of the communications strategy was to be transparent and open so COPHES recommended that each country report-back all results even though for some of the chemicals (e.g. some of the phthalate metabolites) no guidelines were available. Many others have recommended or taken this approach and provided the results first to the study individuals, then announcing the aggregate results nationally and to the broader scientific community (Brody et al., 2014; Emmett et al., 2009; Haines et al., 2011; NRC, 2006; Schoeters et al., 2012).

Before communicating the results of a HBM study consideration needs to be given to the meaning of the results and how to communicate the potential health relevance or convey where there was a lack of scientific understanding (Brody et al., 2014; NRC, 2006). COPHES provided guidance on interpreting results but appreciated that each country would need to make their own decisions based on national policies. Senior researchers should play a role in interpreting results (Brody et al., 2014) and as not all the countries involved had expertise in HBM studies, the experienced countries could provide guidance and advice, facilitated using web conferences.

Expressing the implications and any uncertainties of the results to policy makers is also necessary for them to translate accurately the results into policy (Hart et al., 2010). Publicity from the start of the study and wide dissemination of the results to policy makers and a range of stakeholders, including researchers, industry, scientific regulatory agencies, advocate groups at national, EU and worldwide level has helped to raise awareness of HBM and its potential. Requests for the study data and advice on other HBM protocols have been received and there is growing interest for a future European wide HBM approach.

5. Conclusions

A communication strategy should include a project plan with deadlines and milestones with a clear plan for dissemination of results. It should be seen as a living document and subject to regular review to ensure that it adapts and remains sensitive to the on-going evaluation of communications activity. Communication needs to be considered right from the start of the study and so the research team needs to be multidisciplinary. Technology/media specialists can provide advice on the use of communication technologies and social media to enhance response rates. Social scientists can run public insight research and assist with community engagement and risk communication. Participants should receive individual results, unless they refuse to be informed, along with guidance on what the results mean. This should acknowledge the uncertainties, provide information on actions to take and be consistent with public health policy.

Effective and timely communication at all stages of a HBM study, not only to the study participants but also to the general public, policy makers and other key stakeholders, is essential if the potential value of HBM is to be realised (Sepai et al., 2008). That is, the successful translation of study results into policy, the facilitation of subsequent HBM studies and ultimately, the improvement of public health.

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References

Adams, C., Brown, P., Morello-Frosch, R., Brody, J.G., Rudel, R., Zota, A., Dunagan, S., Tovar, J., Patton, S., 2011. Disentangling the exposure experience: the roles of community context and report-back of environmental exposure data. J. Health Soc. Behav. 52, 180–196. http://dx.doi.org/10.1177/0022146510395593.

Arendt, M., 2008. Communicating human biomonitoring results to ensure policy coherence with public health recommendations: analysing breastmilk whilst protecting, promoting and supporting breastfeeding. Environ. Health 7 (Suppl. 1), S6. http://dx.doi.org/10.1186/1476-069X-7-S1-S6.

Balazs, C.L., Morello-Frosch, R., 2013. The three R's: how community based participatory research strengthens the rigor, relevance and reach of science. Environ. Justice 6 (1), 9–16. http://dx.doi.org/10.1089/env.2012.0017.

Bates, M.N., Hamilton, J.W., LaKind, J.S., Langenberg, P., O'Malley, M., Snodgrass, W., 2005. Workgroup report: Biomonitoring study design, interpretation, and communication – lessons learned and path forward. Environ. Health Perspect. 113, 1615–1621. http://dx.doi.org/10.1289/ehp.8197.

Becker, K., Seiwert, M., Casteleyn, L., Joas, R., Joas, A., Biot, P., Aerts, D., Castano, A., Esteban, M., Angerer, J., Koch, H.M., Schoeters, G., Den Hond, E., Sepai, O., Exley, K., Knudsen, L.E., Horvat, M., Bloemen, L., Kolossa-Gehring, M., Consortium, D., 2014. A systematic approach for designing a HBM pilot study for Europe. Int. J. Hyg. Environ. Health 217, 312–322. http://dx.doi.org/10.1016/j.ijheh.2013.07.004.

Bellanger, M., Pichery, C., Aerts, D., Berglund, M., Castano, A., Cejchanova, M., Crettaz, P., Davidson, F., Esteban, M., Fischer, M.E., Gurzau, A.E., Halzlova, K., Katsonouri, A., Knudsen, L.E., Kolossa-Gehring, M., Koppen, G., Ligocka, D., Miklavcic, A., Reis, M.F., Rudnai, P., Tratnik, J.S., Weihe, P., Budtz-Jorgensen, E., Grandjean, P., Demo/Cophes, 2013. Economic benefits of methylmercury exposure control in Europe: monetary value of neurotoxicity prevention. Environ. Health 12, 3. http://dx.doi.org/10.1186/1476-069X-12-3.

Brody, J.G., Dunagan, S.C., Morello-Frosch, R., Brown, P., Patton, S., Rudel, R.A., 2014. Reporting individual results for biomonitoring and environmental exposures: lessons learned from environmental communication case studies. Environ. Health 13, 40. http://dx.doi.org/10.1186/1476-069X-13-40.

Brody, J.G., Morello-Frosch, R., Brown, P., Rudel, R.A., Altman, R.G., Frye, M., Osimo, C. A., Perez, C., Seryak, L.M., 2007. Improving disclosure and consent: "is it safe?": new ethics for reporting personal exposures to environmental chemicals. Am. J. Public Health 97, 1547–1554. http://dx.doi.org/10.2105/AJPH.2006.094813.

Brown, P., Brody, J.G., Morello-Frosch, R., Tovar, J., Zota, A.R., Rudel, R.A., 2012. Measuring the success of community science: the northern California household exposure study. Environ. Health Perspect. 120, 326–331. http://dx.doi.org/10.1289/ehp.1103734.

Cargo, M., Mercer, S.L., 2008. The value and challenges of participatory research: strengthening its practice. Annu. Rev. Public Health 29, 325–350. http://dx.doi.org/10.1146/annurev.publhealth.29.091307.083824.

Casteleyn, L., Dumez, B., VanDamme, K., Anwar, W.A., 2013. Ethics and data protection in human biomarker studies in environmental health. Int J Hyg Environ Health. 216, 599–605. http://dx.doi.org/10.1016/j.ijheh.2013.03.016.

Casteleyn, L., Dumez, B., Becker, K., Kolossa-Gehring, M., Den Hond, E., Schoeters, G., Castaño, A., Koch, H.M., Angerer, J., Esteban, M., Exley, K., Sepai, O., Bloemen, L.,

Horvat, M., Knudsen, L.E., Joas, A., Joas, R., Biot, P., Koppen, G., Dewolf, M.-C., Katsonouri, A., Hadjipanayis, A., Cerna, M., Krskova, A., Schwedler, G., Fiddicke, U., Nielsen, J.K.S., Jensen, J.F., Rudnai, P., Kozepesy, S., Mulcahy, M., Mannion, R., Gutleb, A.C., Fischer, M.E., Ligocka, D., Jakubowski, M., Reis, M.F., Namorado, S., Lupsa, I.-R., Gurzau, A.E., Halzlova, K., Jajcaj, M., Mazej, D., Tratnik Snoj, J., Posada, M., Lopez, E., Berglund, M., Larsson, K., Lehmann, A., Crettaz, P., Aerts, D., A pilot study on the feasibility of European harmonized human biomonitoring: challenges and opportunities. Environ. Res. http://dx.doi.org/10.1016/j.envres.2014.10.028, in this issue.

Cyprus Presidency of the Council of the European Union, 2012a. Proceedings of the Conference on Human Biomonitoring: Linking Environment to Health and Supporting Policy, Larnaca, October 23–24. ⟨http://www.moh.gov.cy/MOH/SGL/sgl.nsf/E9C340D26CBE381DC2257B8A0036BD23/$file/HBM%20CY%20Presidency%20Booklet%20final%20as%20printed.pdf⟩ (accessed 05.09.14).

Cyprus Presidency of the Council of the European Union, Press release-European projects measure chemicals in people across Europe for the first time, 2012b. ⟨http://www.cy2012.eu/index.php/en/news-categories/press-release-european-projects-measure-chemicals-in-people-across-europe-for-the-first-time⟩ (accessed 05.09.14).

DEMOCOPHES, 2013a. Human Biomonitoring on a European Scale, Layman's report. ⟨www.eu-hbm.info⟩, (accessed 05.09.14).

DEMOCOPHES, 2013b.Technical report demonstration of a study to coordinate and perform human biomonitoring on a European scale. ⟨http://www.eu-hbm.info/euresult/democophes-short-technical-report⟩ (accessed 05.09.14).

Emmett, E.A., Zhang, H., Shofer, F.S., Rodway, N., Desai, C., Freeman, D., Hufford, M., 2009. Development and successful application of a "community-first" communication model for community-based environmental health research. J. Occup. Environ. Med. 51, 146–156. http://dx.doi.org/10.1097/JOM.0b013e3181965d9b.

Esteban, M., Schindler, B.K., Jiménez-Guerrero, J.A., Koch, H.M., Angerer, J., Rivas, T. C., Rosado, M., Gómez, S., Casteleyn, L., Kolossa-Gehring, M., Becker, K., Bloemen, L., Schoeters, G., Den Hond, E., Sepai, O., Exley, K., Knudsen, L.E., Horvat, M., Joas, A., Joas, R., Aerts, D., Biot, P., Pirard, C., Wittsiepe, J., Jones, K., Nielsen, F., Grander, M., Janasik, B., Borošová, D., Davidson, F., Dumitrascu, I., Fischer, M.E., Kašparová, L., Larssen, T., Naray, M., Hohenblum, P., Plateel, G., Tratnik, J.S., EQUAS Reference Labs, Castaño, A., . Mercury analysis in hair: comparability and quality assessment within the transnational COPHES/DEMOCOPHES project. Environ. Res. http://dx.doi.org/10.1016/j.envres.2014.11.014, in this issue.

European Commission, 2012. Open Days 2012. In: Proceedings of the Local Events of the European Union Committee of the Regions. ⟨http://ec.europa.eu/regional_policy/conferences/od2012/doc/le_proceedings_2012.pdf⟩ (accessed 05.09.14).

Fiddicke, U., Becker, K., Schwedler, G., Seiwert, M., Joas, R., Joas, A., Biot, P., Aerts, D., Casteleyn, L., Castaño, L., Esteban, M., Angerer, J., Koch, H.M., Schoeters, G., Den Hond, E., Sepai, O., Exley, K., Knudsen, L.E., Horvat, M., Bloemen, L., Katsonouri, A., Hadjipanayis, A., Cerna, M., Krskova, A., Mørck, T.A., Rudnai, P., Kozepesy, S., Mulcahy, M., Mannion, R., Gutleb, A.C., Fischer, M., Ligocka, D., Jakubowski, M., Namorado, S.M., Reis, M.F., I-R., Gurzau, A.E., Halzlova, K., Jajcaj, M., Mazej, D., Snoj Tratnik, J., Rivas, T.C., Gómez, S., Berglund, M., Larsson, K., Lehmann, A., Crettaz, P., Kolossa-Gehring, M. Lessons learnt on recruitment and fieldwork from a pilot European human biomonitoring survey http://dx.doi.org/10.1016/j.envres.2014.08.039, in this issue.

German Human Biomonitoring Commission, 2012. [Substance monograph on bisphenol A (BPA)-reference and human biomonitoring (HBM) values for BPA in urine. Opinion of the Human Biomonitoring Commission of the German Federal Environment Agency (UBA)]. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz, 55, 1215–1231. doi: 10.1007/s00103-012-1525-0.

Haines, D.A., Arbuckle, T.E., Lye, E., Legrand, M., Fisher, M., Langlois, R., Fraser, W., 2011. Reporting results of human biomonitoring of environmental chemicals to study participants: a comparison of approaches followed in two Canadian studies. J. Epidemiol. Community Health 65, 191–198. http://dx.doi.org/10.1136/jech.2008.085597.

Hart, A., Gosling, J.P., Boobis, A., Coggon, D., Craig, P., Jones, D., 2010. Development of a framework for evaluation and expression of uncertainties in hazard and risk assessment. Final report of Food Standards Agency Project number T01056. Food Standards Agency. http://www.food.gov.uk/science/research/foodcomponentsresearch/t01programme/t01projlist/t01056#.UlbULdIqj (accessed 05.09.14).

JECFA, 2006. Compendium of food additive specifications: Joint FAO/WHO Expert Committee on Food Additives (JECFA). In: Proceedings of the 67th Meeting of the Food & Agriculture Org.

Joas, R., Casteleyn, L., Biot, P., Kolossa-Gehring, M., Castano, A., Angerer, J., Schoeters, G., Sepai, O., Knudsen, L.E., Joas, A., Horvat, M., Bloemen, L., 2012. Harmonised human biomonitoring in Europe: activities towards an EU HBM framework. Int. J. Hyg. Environ. Health 215, 172–175. http://dx.doi.org/10.1016/j.ijheh.2011.08.010.

Keune, H., Morrens, B., Loots, I., 2008. Risk communication and human biomonitoring: which practical lessons from the Belgian experience are of use for the EU perspective? Environ. Health 7 (Suppl. 1), S11. http://dx.doi.org/10.1186/1476-069X-7-S1-S11.

Morello-Frosch, R., Brody, J.G., Brown, P., Altman, R.G., Rudel, R.A., Perez, C., 2009. Toxic ignorance and right-to-know in biomonitoring results communication: a survey of scientists and study participants. Environ Health. 8, 6. http://dx.doi.org/10.1186/1476-069X-8-6.

NRC, 2006. Human biomonitoring for environmental chemicals National Research Council, Committee on Human Biomonitoring for Environmental Toxicants. National Academies Press, Washington, DC.

O'Fallon, L.R., Dearry, A., 2002. Community-based participatory research as a tool to advance environmental health sciences. Environ. Health Perspect. 110 (Suppl. 2), S155–S159.

Reis, M.F., Segurado, S., Brantes, A., Simoes, H.T., Melim, J.M., Geraldes, V., Miguel, J. P., 2008. Ethics issues experienced in HBM within Portuguese health surveillance and research projects. Environ. Health 7 (1), S5. http://dx.doi.org/10.1186/1476-069X-7-S1-S5 (Suppl).

Reis, M.F., Tedim, J., Aguiar, P., Miguel, J.P., Casteleyn, L., Joas, R., Van Tongelen, B., 2007. Online integrated solution to collect data, generate information and manage events in the human biomonitoring field. Int. J. Hyg. Environ. Health 210, 403–406. http://dx.doi.org/10.1016/j.ijheh.2007.01.007.

Riboli, E., Haley, N., Tredaniel, J., Saracci, R., Preston-Martin, S., Trichopoulos, D., 1995. Misclassification of smoking status among women in relation to exposure to environmental tobacco smoke. Euro. Respir. J. 8, 285–290.

Schindler, B.K., Esteban, M., Koch, H.M., Castano, A., Koslitz, S., Canas, A., Casteleyn, L., Kolossa-Gehring, M., Schwedler, G., Schoeters, G., Den Hond, E., Sepai, O., Exley, K., Bloemen, L., Horvat, M., Knudsen, L.E., Joas, A., Joas, R., Biot, P., Aerts, D., Lopez, A., Huetos, O., Katsonouri, A., Maurer-Chronakis, K., Kasparova, L., Vrbik, K., Rudnai, P., Naray, M., Guignard, C., Fischer, M.E., Ligocka, D., Janasik, B., Reis, M.F., Namorado, S., Pop, C., Dumitrascu, I., Halzlova, K., Fabianova, E., Mazej, D., Tratnik, J.S., Berglund, M., Jonsson, B., Lehmann, A., Crettaz, P., Frederiksen, H., Nielsen, F., McGrath, H., Nesbitt, I., De Cremer, K., Vanermen, G., Koppen, G., Wilhelm, M., Becker, K., Angerer, J., 2014. The European COPHES/DEMOCOPHES project: towards transnational comparability and reliability of human biomonitoring results. Int. J. Hyg. Environ. Health 217, 653–661. http://dx.doi.org/10.1016/j.ijheh.2013.12.002.

Schoeters, G., Den Hond, E., Colles, A., Loots, I., Morrens, B., Keune, H., Bruckers, L., Nawrot, T., Sioen, I., De Coster, S., Van Larebeke, N., Nelen, V., Van de Mieroop, E., Vrijens, J., Croes, K., Goeyens, K., Baeyens, W., 2012. Concept of the Flemish human biomonitoring programme. Int. J. Hyg. Environ. Health 215, 102–108.

Schulz, C., Angerer, J., Ewers, U., Kolossa-Gehring, M., 2007. The German Human Biomonitoring Commission. Int. J. Hyg. Environmental Health 210, 373–382.

Schulz, C., Wilhelm, M., Heudorf, U., Kolossa-Gehring, M., 2011. Update of the reference and HBM values derived by the German Human Biomonitoring Commission. Int. J. Hyg. Environ. Health 215, 26–35.

Sepai, O., Collier, C., Van Tongelen, B., Casteleyn, L., 2008. Human biomonitoring data interpretation and ethics; obstacles or surmountable challenges? Environ. Health 7 (Suppl. 1), S13. http://dx.doi.org/10.1186/1476-069X-7-S1-S13.

Washburn, R., 2014. Measuring personal chemical exposures through biomonitoring: the experiences of research participants. Qual. Health Res. 24 (3), 329–344. http://dx.doi.org/10.1177/1049732314521899.

WHO, 1996. Biological Monitoring of Chemical Exposure in the Workplace Guidelines. World Health Organization, Geneva.

Wu, N., McClean, M.D., Brown, P., Aschengrau, A., Webster, T.F., 2009. Participant experiences in a breastmilk biomonitoring study: a qualitative assessment. Environ. Health 8, 4. http://dx.doi.org/10.1186/1476-069X-8-4.

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